

## **AMCHP Annual Conference, 2010**

### **Moving Ahead Together:**

#### **Celebrating the Legacy, Shaping the Future of Maternal and Child Health**

##### **Making the Culture and Proving Dependency Outcomes –**

##### **A Focus on Tobacco Cessation Quit Lines and HIV Hotlines**

March 6-10, 2010

PATTY DIETZ: Well thank you all for coming today. I know it's a beautiful day out there and there's a lot going on. So we appreciate you coming to this presentation. This whole workshop, which is making the call term \*\*\*\* the outcomes about this on Tobacco Cessation quit lines and HIV hotlines.

So this is session ID I2, and it's eligible for continuing education. If anyone is planning to do that, immediately after this session, you can access online the continuing education and signup for CM use.

My name is Patty Dietz and I am an epidemiologist and a team leader, the Division of Reproductive Health. And we've got five excellent speakers today, two of which are addressing HIV hotlines and three which will address Tobacco Cessation quit lines. And even though we're addressing two distinct topics we're focusing on a service delivery system in that they're all addressing something that is free, that's accessed by telephone and it's designed to improve care to pregnant women.

So I'm going to introduce the speakers, and each of them will talk for about ten minutes, and then we'll save questions for the end. So please write down your questions so you don't forget after each presenter speaks. And then, as I mentioned, there are handouts in the back

So our first two speakers, Shannon Weber, and Laurie Ayala will be addressing the topic of HIV hotlines. And Shannon is the perinatal HIV hotline coordinator at the National HIV AIDS Clinician's Consultant Center at the University of California in San Francisco General Hospital. And in this role Shannon coordinates a national network of perinatal HIV providers, who provide HIV positive pregnant women with critical access to appropriate care.

Laurie Ayala, since 2005 has been the coordinator for the 24/7 Illinois Perinatal HIV hotline. And in this role she oversees the daily operations of the hotline, including triaging medical consultants and case managers to provide services to HIV infected pregnant women and their infants.

So please welcome Shannon.

SHANNON WEBER: Thank you. So to begin with I'm going to give a few slides background about the perinatal HIV epidemic in the United States to give you a bit of a framework for how the telephone consultation servers can be helpful. This slide shows the estimated number of perinatal acquired AIDS cases in the United States, and as you

can see this one of the greatest public health success stories in the HIV AIDS epidemic. Since 1992, which is the peak of the transmissions, HIV case rates among infants has steadily declined, in fact it's been a 95 percent reduction, and this due to CDC promoting HIV testing in pregnancy as well the use of antiretroviral drugs for the pregnant mom and for the exposed infants. You'll see at the end of this slide that there's a slight uptick in the numbers and that is from between 2004 and 2005, and there's not data available for the \*\*\*\* years, but preliminary data tells us that perinatal transmissions are slightly increasing in the United States, and that overall more HIV positive pregnant women are giving birth. It's estimated that between 7 and 8,000 positive women give birth each year. Now in the United States by following the recommendations, so with testing and with antiretroviral drug use the transmission rate can be brought down to less than one percent.

This is AIDS case rates per hundred thousand for female adults and adolescents in the United States. And I put this slide in to just give you a visual, particularly with the color, about where there's higher prevalence of AIDS among women in this country. The highest case rates of AIDS are in the District of Columbia, Maryland, New York, and Florida. And the lowest case rates are in the Midwest except for the state of Illinois. Now the one \*\*\*\* with this slide is that AIDS is a reportable illness, and HIV is not, and there is some data about HIV case rates among women, but to make it simple I just put up this one slide. So this doesn't include all the of the infected women in this country, it shows though, in fact, the women who are the sickest, who have had HIV the longest. But it gives you a very good picture about where HIV is in this country for women.

The timing of mother to child transmission, I think, is important for this audience to understand, because the positive in this slide is the message that it's never too late to intervene. We learn that most of perinatal transmissions occur during that labor and delivery period; right? The huge majority. Now there are cases of transmission that occur earlier, so the earlier a woman is tested and the earlier that she's on antiretroviral drugs the better, and the healthier that she is when she delivers the better. But it's never too late. So even for women that are not engaged in prenatal care or show up to labor and delivery without a documented HIV test we can still dramatically reduce her transmission risk by testing and treating at that point.

This shows the chain of events that leads to an HIV infected child. And the inverse of looking at this is that when we have -- find a HIV infected child and do a case study, we invariably find numerous missed opportunities. Occasionally there are cases where we find that everything was done right and child still is infected with HIV, but generally and overwhelmingly so there are numerous missed opportunities. And this slide puts out bullet point by bullet point what are the interactions that the woman has with the healthcare system with clinicians or with a case worker, or the opportunities that we might have as providers to either test, treat, or provide service to her to decrease the chance that her child will be infected with HIV.

So to help support clinicians in providing the best quality care the perinatal HIV hotline was launched with two goals, one to provide clinical consultation, and we do that

through direct access with clinicians. We're based at San Francisco General Hospital, part of the UCSF system and our clinicians are infectious disease doctors, OB, internal medicine, and family practice doctors with specialty in HIV, who are able to provide a customized clinical consultation to any provider who calls are free hotline.

Additionally, we have a clinicians network and through this we're able to connect callers back with local and regional resources. We're able to do this because it's based on the infrastructure of the warm line and the pep line. Some of you may be familiar with the pep line, it's the National Needle Stick and Blood Splash hotline. These hotlines have been in existence for about 15 years and \*\*\*\* and CDC funded.

This is a GO map that shows the volume of calls that we receive from around the country, and I put this in here to show you something, two distinctly different things. One, you'll see that this very much mirrors the slide I showed you earlier where HIV case rates are high among women, which is also generally where they're higher among men as well. But I want you to know that this mirrors where the epidemic is in this country, but you might also see some of these red triangles, so ten or more calls coming from some rural areas. So this also tells us something about the needs of providers in those areas where the HIV and AIDS case rates may not be as high, but there are people living there and there are providers providing service that need clinical consultation.

This will show you that in general our call volume and our network connections have steadily increased since we launch the prenatal HIV hotline in 2005. And this slide shows that there's a variety of specialty of callers that need support and assistance. So among physicians, which are the bulk of our callers, it's almost evenly divided between infectious disease doctors, primary care doctors, and OB/GYNS. You'll see a smaller percentage of pediatricians, and that makes sense because of what we learned earlier; right? It's generally HIV exposed infants and not infected infants in this country. So the calls we get from pediatricians are about testing or maybe vaccines and followup care. We also receive calls from nurse practitioners, midwives, and physicians assistants.

This is one of my favorite data slides from the hotline. This shows HIV patient load of our callers. And something that you would expect to see, I think, are these first two columns. That the number of callers who have five or less patients is 40 percent. That makes sense; right? Someone who doesn't care for HIV patients very much, you would expect the to need clinical consultation. What was surprising to me when we first ran these numbers five or so years ago, and remains consistently the same is that almost half of our calls are from callers who have more than 26 HIV positive patients. Meaning we would generally expect those folks to be expert, and they are, they're specialists and experts in their area and in their field. Yet perinatal HIV care is nuanced, and it's very individual, and there's lots factors that weigh into how a woman should be best cared. And so what we've learned from this is that it's both very inexperienced and well as experienced providers who need clinical consultation to provide the best quality care for their patients.

I put this call up to just give an example of a type of call that we'll receive on the hotline. We receive calls on a variety of topics, everything from preconception and \*\*\*\* care to \*\*\*\* testing questions, and what kind of antiretroviral drugs should be used in pregnancy. The hotline is particularly important for women who show up to labor and delivery without prenatal care and there's very time sensitive issues involved. But this is kind of a basic call about a woman who's diagnosed with HIV at 24 weeks of pregnancy, and she's having problems with the medications that she was prescribed, which was a guideline based regimen and the clinician calls up to find out what they should do. And so our clinician is able to help them, you know, give them a response and tell them, "You need to have AZT as part of the regimen," but as she's having maternal toxicities in this case provide another regimen that would be appropriate.

I mentioned earlier one of our other services that is the perinatal HIV clinicians network and it's a national directory of providers that are able to assist callers with a one-time consultation. They can co-manage the case, or they can accept complete referral of care. In the little vignette that I'll share with you with that is a fabulous, one of my most favorite opportunities that I've had to connect someone with care, is that a family physician had a patient in his practice who is known HIV positive and she became pregnant, and it was her fourth pregnancy. She had three other children at home, but she was new to this area. The nearest perinatal HIV -- so it was an academic specialty program was several hours away and required a plane flight for her to get there. And this program wanted her to come and live in their city for the last month of her

pregnancy, and the deliver at the academic hospital. And this woman said that she wanted to stay at home, and she became slightly more adamant about that saying, “No, you know, I will stay with my kids and my family.” And this family physician, a wonderful guy who had lots of experience with HIV care but not a lot of OB experience, told us, “I’m willing to care for this woman if you can find someone else that will help manage the OB piece.” And so I called around and was able to find a midwife who was recently practicing midwife, who had done her training at an urban setting, and she had encountered HIV positive patients before, so she was afraid to try, and she was young, and so she wasn’t afraid to try something new. And so what we did is we paired this family physician and the midwife together and then gave them a specific clinician on our hotline that they called and spoke with every time. And they were to all three co-manage this case. And the woman was able to stay at home, deliver in her medical home, so with providers that she was comfortable with, and deliver and HIV negative baby.

One final resource that we provide for clinicians is on our website. We have a compendium of HIV testing laws. You can click on your state and it pulls down a PDF of all the relevant laws, and in the very small print you can hardly see on the left there’s a perinatal quick reference guide. So there are all of the perinatal laws are grouped in a separate but one downloadable PDF, so this can be very helpful for you as you’re advocating for routine perinatal HIV screening in your area. Thank you.

LAURIE AYALA: Good afternoon. Like Shannon I coordinate a perinatal HIV hotline but in contrast to her our hotline is for the state of Illinois. It’s not a national hotline, it’s a



state level hotline. And I'm going to talk to you a little bit about what that experience is like.

I want to start by just giving you a bit of context for HIV in Illinois. So HIV \*\*\*\* prevalence in Illinois is one per one thousand, but we do see higher \*\*\*\* prevalence in Chicago at three per one thousand, and then also in Cook County which is basically suburban Chicago. And also in the east St. Louis area, which is southwest, the southwestern part of our state near St. Louis, Missouri.

So in summary, Illinois is considered a jurisdiction with elevated HIV incidence. Our hotline as I said a statewide resource and we provide and social service providers -- our statewide resource for medical and social service providers caring for HIV positive pregnant women. To our knowledge we are the only state level perinatal HIV hotline in the country.

Our services include real time medical consultation on HIV related obstetric and pediatric issues, much like the national hotline provides medical consultation. And we also actively link positive women who are pregnant and their infants to medical caring case management during and after pregnancy. And I'll talk in few minutes about how that linkage is done. And one of the unique aspects of what we do is we act as a reporting mechanism for the state of Illinois for positive rapid HIV tests that are performed in labor and delivery units throughout our state. So without going into a great detail the state of Illinois requires any woman who presents to labor and delivery without

a document HIV status to be counseled and offered or recommended a rapid HIV test. And any of those tests that turn out positive have to be reported, by law, to us within 24 hours. And the motivation behind that being it allows an opportunity to provide medical consultation as needed and also assures that there is support to link that mother and her exposed infant to followup care and services.

When I talk about the perinatal HIV hotline I can't talk just about the hotline, because the state of Illinois has created this sort of model of perinatal HIV prevention, that we call the safety net of prevention. And the hotline is an integral part of that, but there are two other programs I just want to briefly describe, so you can understand sort of how we do our work in Illinois. The perinatal rapid HIV testing initiative is an initiative, an experience in the state of Illinois in which rapid HIV testing in labor and delivery was implemented in every single labor and delivery unit in the state of Illinois, so there's over 130 birthing hospital in the state. And then the other program is the enhanced perinatal HIV case management program, and that's an intensive case management program that links a positive pregnant woman with a dedicated case manager during and after pregnancy.

This model, this sort of safety net of prevention has actually be recognized by The Centers for Disease Control as a model program for state level perinatal HIV prevention work. And I just want to talk a little about this safety net was developed. I don't know how many in the audience work in perinatal HIV in their states, but I think there's certainly some lessons to be learned for how this all came about in our state.

So very briefly in 2000 the pediatric \*\*\*\* of Chicago Prevention Initiative, which we call PACPI was formed as a not for profit organization to help eradicate mother to child transmission of HIV in Chicago. And in 2002 PACPI began offering this intensive case management program for the highest risk HIV positive women, those at highest risk of transmitting the virus to their children. In 2003 the rapid testing implementation initiative was created, again one of the few states, and Shannon can probably refer better to what's going on in the rest of the country, but one of the few states that actually has rapid testing ongoing in every labor and delivery unit in their state. And then in 2003 the perinatal HIV hotline was created to link these hard to reach women in the Chicago land area to the care and services that they need, as well as to provide real time medical consultation. In 2005, the hotline received funding from our state's Department of Public Health to expand to become a statewide resource. And the only reason I sort of go through all of this is to sort of illustrate for you the different pieces that are involved in this comprehensive safety net that's been created and to emphasize that the key to all of this really is the collaboration among the three programs. We have routine communication between all of these programs, which really allow us to address issues from multiple perspectives related to testing and linking women to care. And it allows us to maximize what is always limited resources to support institutions who are testing women and also to support the linkage to care for the women and the exposed newborns. In the case of the hotline we do our work with one FTE, and then collaboration with the organization that I've described, and kind support from our

partners and medical staff at the hospital that we work with. So we basically run ourselves on a shoestring budget.

This is our program website and I don't know if you can see the address. It's [hivpregnancyhotline.org](http://hivpregnancyhotline.org) and this we launched in March 2009 really as a resource for medical and social service providers in Illinois. It has all the information about our programs, about rapid testing in this state, access to forms that Illinois providers might need, but beyond that it also has just real general information about care and treatment for HIV infected women. So I invite any of you who work with that population to take a look.

I'm just going to share a couple of data slides with you due to our limited time, but this is our call volume by year since the program started in 2005, and you can see that our call volume has increased dramatically. And what's been most positive about our call volume has been this increasing proportion that we've had of calls during the \*\*\*\* period. So women are being identified to us increasingly earlier in pregnancy, not when they're delivering, not after they've delivered because they had a rapid HIV test, but during the prenatal period, which of course allows us much more of an opportunity to intervene for the benefit of the health of the mother and her child. And a lot of this is also is reflection of women in Illinois increasingly having a documented HIV status before they even get to labor and delivery, and providers being aware of our services and calling us that time.

And this slide is just showing you the number of women that are linked to care by the hotline over time. Every year we link around 30 or so women to care. And while that may seem like a huge number of women, what's important to recognize is that our hotline is focused on the highest risk population. So an HIV infected woman who's willing to care is not going to be identified to us, but someone who's really at risk of falling through the cracks in the healthcare system and not getting the appropriate care and the appropriate antiretroviral treatment, and obstetrical care that she needs will be identified to us. And so those 30 women approximately yearly that are linked to care as a result of our work.

I wanted to share a case summary with you. Just to sort of illustrate sort of what we do and the types of services that we can provide and the response that we can provide. So in this case, Angela was 32 weeks pregnant when she went to the hospital with abdominal pain, and she came out with a positive rapid HIV test. The hospital called the hotline to report the test result. What happened next? Well the hospital did the right thing, because by law in our state they must call us to report this positive rapid test, and then there were a number of things that we were able to do. The hotline staff contacted Angela's obstetrician, she consented to that, and we were able to talk to her obstetrician prior to a visit that she had scheduled for that same afternoon. This obstetrician was inexperienced in the care of HIV positive pregnant women, quite frankly, a little freaked out that he had to deliver these test results to this patient and talk to her about the next steps. And so we were able to send of our case managers to meet with Angela and her doctor during that visit. And what was great about this is that the case manager was

able to obviously support Angela who was coming to terms with a completely unexpected diagnosis of HIV, but also for the provider who wasn't quite sure how to handle things, and certainly, if the patient gets off on the wrong foot initially with this diagnosis there's going to be a lot of ground to make up as she moves forward. So it was a really positive interaction that took place. She was confirmed positive, HIV positive, and she was linked to a perinatal HIV center for state of the art integrated HIV OB care in Chicago. With her case manager's support she was able to accept her diagnosis and all that that entailed cause it's tremendous implications not only being pregnant, coming to terms with being infected, who may infected her, what that means for life and for her family. She was able to care for herself. She attended all her prenatal appointments, and she gave birth to a healthy baby boy, who's HIV negative.

I want to conclude by sort of emphasizing that for our experience in Illinois the hotline has been an essential piece of it. We're really the lynch pin between the rapid testing and the case management that is out there and in existence for women our state. But our experience is absolutely replicable to other states. So the hotline, a hotline provides an opportunity to do a lot of different things, medical consultation linkage to care, reporting requirements, and providing that service for state. So there's a lot of opportunity and potential in statewide perinatal HIV hotline. And I encourage you learn more if you're interested in developing some type of hotline in your state, and of course, welcome any questions you might have at end.

PATTY DIETZ: Thank you very much. That was great. We're now going to shift gears and move on to tobacco cessation, and I'm going to introduce the three speakers we have. Our first one is Robert Anderson, and he is a co-investigator at West Virginia University, the prevention research center. And he works closely with the State Division of Tobacco Prevention, and is the project manager of the CDC funded project titled Fax to Quit, Smoking Cessation among pregnant women. We'll then hear from Heather Jordan. She is a research specialist at the University of Medicine and Dentistry in New Jersey at the Center for Tobacco Surveillance and Evaluation Research. She is the project manager of the CDC funded, Increasing New Jersey Quit line Use by Pregnant Postpartum Smokers Knowledge and Barriers. She has been responsible for developing the key informant interview guide conducting interviews, developing and administering the provider survey and analysis of data. And then finally, we'll hear from Kate Kobinsky, who for three years has managed the Wisconsin Tobacco quit line at the University of Wisconsin Center for Tobacco Research and Prevention. Prior to this she managed The First Breath program, a statewide prenatal smoking cessation program that is nationally recognized. And she's a project manager of the CDC funded project of Evaluation of Pregnant and Postpartum Women's Use of Wisconsin Fax to Quit program.

So first we will from Bob.

Robert Anderson: Good afternoon. Good to talk to you today. This is a project that began early last year. I want to acknowledge the co-investigators and the sponsor that funded this project with \*\*\*\* to quit. I want to first go over some of the basic things that

we know about what smoking can do. You see some of the problems it causes, reduced fertility, preterm deliver, low birth weight, \*\*\*\* fetal birth, fetal growth, and preterm related death and SIDS. And those are just some of the many things that are problems. Not to mention secondhand smoke and other issues as well. This map shows you by color where the problem is most pronounced. Whatever this darker color is where it's heaviest, where more 60 percent of births were reported to be born to pregnant smokers in 2003. Probably my state was ahead, at least a country, you can see in the bottom, in 2003 it was 26.1 percent, and right now it's about 27 percent, still the highest by far of any state in the country. We do know what happens to a lot of women when they find out that they're pregnant. As many as half of them quit right away. And about one out of eight will quit later on during the pregnancy. Some of them will quit, some of them will cut down, some them won't do anything. I know some women who actually told me they smoked more when they became pregnant because of the stress that was involved with that. I'm not making this up. And of the women who do quit during pregnancy most of them are going to relapse sometimes on the way out of the hospital, sometime within a month or two. Women sometimes say that they don't quit smoking, they just stop for a while. We haven't been able to figure out how to sustain even those who do quit. And our problem is most of them don't even try.

Well the idea of this project was to take advantage the telephone based quit lines. Every state in the country has one. They began about 2006 and in some states earlier than that. They're free. You don't have to go anywhere. You can do it all by phone, of course. They're convenient. And most quit lines have long hours. Some quit lines are 24/7, but



maybe with the budget cutbacks that's no longer the case. The phone coaches are very highly skilled, highly well trained, and all states have one, but they're not all the same. Most states do not offer nicotine therapy with quitting, our does, but most do not. And the criteria for being helped isn't uniformed. Sadly not everybody can call a quit line in their state and get help. In some cases there are criteria which rule that out from happening.

I'll briefly go through what we did and what our results were during this first year. We know that in our state women have a very high unmet need for smoking cessation. We have the highest rate of smoking in pregnancy, and we're, I think, second to Kentucky in overall smoking right now. Pretty high. So last February we began this process. We wanted to see if we could establish a collaborative of stakeholders, which were the university, the OB providers, the state, the health department, and the quit line itself. We developed the Fast To Quit protocol, and then we assessed how it worked, was it feasible, what was the impact, and then we're doing things like this to share what we have found out.

This map shows the three counties that part in the Fax To Quit project. The county in the middle is where Morgantown is, where we are, and we use the OB clinic and the hospital attached our medical school. The county on the right is Preston County, that was a small clinic that was run by a nurse practitioner, who two months into the project closed her practice and moved to Virginia. So we lost that site. And the other county is a small group practice in Fairmont, West Virginia. They do about 300 women a year. Our clinic in Morgantown does over 1000. It's one of the largest in the state. So last

February when we brought in two MDs from \*\*\*\* University who gave the CMEs on all of the smoking cessation guidelines, particularly, with an eye, and an ear, and mouth towards those who are working with pregnant women. Each clinic's role was to screen the patients for smoking, to do the typical things that they were trained how to do, and if they found patients who were interested in quitting and willing, they then AIDSed the following form to the clinic, to the quit line, which is based in Charleston, West Virginia. And the handout may not be that clear. If want an actual copy you can email me and I'll send it to you, but it's pretty straightforward. We're going to be maybe moving toward eAIDSing an \*\*\*\* quit type thing electronically in the future, but right now everything is still done by paper.

I won't go through this chart since it's in your handout, so to save us some time, I'll get to this part of it. What we found in the first aspect of this project that 57 women were referred by the obstetricians between March and December of last year. That means some of the have not delivered their babies as yet. Now when we talked about this project with \*\*\*\* a while back, they said, "Bob half of the women who are referred will never even cooperate with the quit line, and half of those who do will never even try to quit." And they weren't too far off. So we certainly weren't the first state to do this. We know what Wisconsin has been doing it for a while, but we thought it was time to try in a state with the most severe problem. And what we found was those who did enroll, most of them all of the were White, they were of a very relatively low age, none of them had finished high school, some of them actually were still in high school. We didn't involve anybody below 18, but the \*\*\*\* of an 18 year old \*\*\*\* that was senior in high school is

they typically live with a smoker, and they were fairly heavy smokers as well. We'll be anxious to see how many actually quit. But we do know this is a very challenging time.

Although one might think that being pregnant -- the one time one might quit smoking and certainly stop alcohol, and all the other things that they're told, but it's easier said than done when you have a habit that's very addictive that many women find enjoyable, and they use it for stress relief. So it is a challenge. And we also found that when tried to involve the obstetricians with this, what we thought would be a fairly modest change in the way they do practice, wasn't as modest as we thought, but of course were not the ones who are running a clinic and doing everything that's involved with that. So we will be refining ways to make this a little bit easier for them to do this in the future. We did find it was very helpful to coordinate the project among office staff and the providers having regular visits to the clinics to talk with them, and very important to keep communicating with them quite frequently. We do believe that this is a feasible thing to do. That there are doctors who will cooperate. There are some who have done more counseling with women than they had done in the past with quitting smoking. Quit line was very, very cooperative in keeping us abreast as to what occurred. We do think that using Fact To Quit could very well increase rates by connecting these women through a quit line. I've no doubt that some of the women who did get on the quit line may not have tried otherwise, and we think it could be a way to bridge the cessation gap, which is quite pronounced in West Virginia. Believe it or not there are physicians who, quite honestly, are very clueless. We're doing some focus groups and some have been giving women very, very bad advice. So we're learning things about that that, I think, can help

us in the future as well. But we do think this does have a good, very good potential. This is poster that we designed that in some of the clinics. And there's my contact information. Thank you.

PATTY DIETZ: Next we'll hear from Heather. While were switching presentations how about everybody stand up and stretch. We're almost done. Stretch. Good job. All right. Okay. Okay.

Heather Jordan: I'm not keen on microphones. Can you all hear me okay? All right. So today I'm going to talking with you about two parts our CDC ASPC cooperative agreement. We are from an academic institution. We're not out there directly doing service provision, so we are very humble to be working with those folks who actually do that service provision on a day-to-day basis. So I'm coming from an academic researcher type of background understanding that service provision is another whole ballgame when you're actually out there in the field.

So today we'll be talking about some of the findings we have from our key \*\*\*\* informant interviews, and the survey we've done with nurse midwives, and OB/GYNs practicing in the state of New Jersey. This is what I'm hoping to get through today. I know it looks very extensive. We'll go as quickly as we can. Quick background information about what's going on in New Jersey. There was a fantastic article that came out with \*\*\*\* data that said that about 16.2 percent of women in New Jersey smoked prior to their pregnancies in the years 2004 and 2005. And of those women about half of them quit

before entering into prenatal care. About 25 percent smoked the same or more during their pregnancy. About 20 percent reduced smoking during their pregnancy, and only 5 percent or so quit smoking while they were in their prenatal care settings, which is quite shocking actually, but that is what the trends are in New Jersey that we have to deal with. Of those women who reported smoking upon entering into prenatal care about 60 percent of them did report discussing the need to quit and how to quit with their provider, but only about 30 percent reported actually setting a quit date with their provider. If anybody out there in the audience is knowledgeable about the clinical practice guidelines, you know there are these things called the five A's, ask, advise, assess, assist, and arrange. In New Jersey we know that providers are asking if women smoke and we know that they're advising them about the need to quit. The problem comes in with the helping them to actually set a quit date and helping follow through with helping those women to quit.

Very quick background information about what's happening in New Jersey in terms of quit services. This talk is going to be talking about quit line. We also have a quit net and quit centers in New Jersey. There's also something called Mom's Quit Connection in New Jersey, which is funded and sponsored through the southern perinatal New Jersey \*\*\*\*. That product is actually not widely used statewide, although it is available for all women in the state of New Jersey. And we've heard a little bit about what Fax To Quit is already. I will note that Fax To Quit is not currently implemented with our telephone quit line. It is implemented with some of our quit centers.

So very quickly the methodology about our key informant interviews, we decided as a research team that it was very, very important to pull together a group of key stakeholders in the state of New Jersey. We didn't want to just jump right in and do a Fax to Quit pilot study. It was not going to work in New Jersey if we tried to do that straightaway. So we created our key stakeholder group and that group has been very informative, very instrumental in the different aspects of our project. They helped us to identify the key informants that we were hoping to be able to interview. We had 22 people identified, and eight of them decided to participate, five nurse midwives, and three OB/GYNs. Those interviews lasted anywhere from 30 minutes to 90 minutes and we did offer an incentive for participation. The interviews covered many, many topics. Here are the two topics within the interviews that I think are most relevant to today's talk.

So very quickly about New Jersey quit line. All of our participants do offer smoking cessation services to their patients, but they all did say that they thought New Jersey quit line would be a helpful adjuvant treatment option, especially those folk who weren't feeling particularly comfortable with offering smoking cessation. I did include some quotes here too, just for you to see. I'm not going to read through them, because we just don't have time. Some of the barriers that were noted about providing referrals include many of our providers do have health educators or certified tobacco treatment specialists right on staff, so they prefer this sort of one stop shop model where they can provide direct patient counseling on site, rather than referring to a quit line. We had some folks who said they just didn't know quit line existed, others saying that they just

forget to mention it when they were in a patient encounter, others saying they wanted materials about quit line available like pamphlets. We did have one person say that a patient reported a negative experience when dealing with the telephone cessation counselor, which is disheartening. And we also have some providers who believe that only English speakers can call the quit line, which is simply not true.

For Mom's Quit Connection none of the folks we interviewed had even heard of it or referred a patient to it, and that could just be because of where they're located within the state of New Jersey. They might not have access or think they access to that quit line that's offered through the south. Barriers to referring to this service once people were informed of it are very similar to what I've already mentioned. They don't know it exists. They don't understand a statewide reach. Again, they prefer that one stop shop model. And also, some of providers said, "You know what? Rather than knowing all about all of these different products that are out there, we're just going to use New Jersey quit line as a clearing house of information." So they don't want to know that we have quit net. They don't know we have Mom's Quit Connection, and they don't want to know we have quit centers. They just want to know the 1-800 quit line number, and they think that once somebody calls that quit line they'll receive the information that they want.

So quickly about Fax To Quit. We did ask a lot of questions about this proposed program of Fax To Quit, and here's just some of the data we found about it. All the participants believe their clinical sites would be able to sustain this type of a program,

and they all said they would use it. They thought that having a Fax To Quit program at their site would help prompt them to do the followup that we know isn't quite happening in prenatal care, which I thought was an interesting finding. They thought it would fit in with their daily tasks. They thought it would be useful for non-English speaking patients. And they also noted that they thought being able to fax a form in to Fax To Quit, and have the counselor call the patient rather than have the patient initiate the call to the quit line would be a plus. We know that sometimes we can give the 1-800 number out these clients or these patients, but they won't actually make the call to the quit line. Many of the participants who use electronic medical records would like a point and click option, we know that there are some barriers to that though, including informed consent and HIPPA things. And then those folks with little or no computer access during a patient encounter said they would prefer just to do the good old fashioned fax method. All of the providers noted that they need to be able to get informed consent from the patient, and then this form would become part of the patient's chart. We also found that most participants would like some form of progress note, they thought that would be helpful, but it's not essential to the program. And then you can see there's some listed things, reasons why progress notes would be helpful. The one that is most important to me as a surveillance and evaluation person is that many of our key informants said, "You know what? We would pilot test Fax To Quit, and we would use those progress notes to help us to evaluate a Fax To Quit works with our patient population." I thought that was a quite insightful comment from those folks.



Noted barriers to Fax To Quit, of course, there's lack of staff, resources are ready, so we're adding one more thing to the list of things to get done. So we would certainly have to be addressing the work flow issue at the sites. Again, they note this lack of available minutes on women's phones, and inability to research postpartum women, and they say, "You know what? If we can't reach these women to do postnatal care, how in the heck is the quit line going to be able to reach these women? And if they can reach them, they're not going to have minutes to talk to you anyway."

So very quickly some discussion points about our interviews. All of the participants that we talked with currently provide some form of tobacco cessation to their patients who smoke. Some of the participants are misinformed about the current services that are out there. There was enthusiasm for the adoption of a Fax To Quit program. And some of the barriers that we found are probably site specific barriers such as work flow issues while others might be systemic such as women not having some available minutes on their cell phones, but we believe that all of these barriers are \*\*\*\*. Some of our recommendations that came out of the interviews include we need to let New Jersey know that they need to have continued efforts to and properly inform the healthcare providers out there of the available smoking cessation services that are in New Jersey right now. We think that pamphlets and other user-friendly materials need to be always be distributed to the providers on a regular basis. And we think that a feasibility study of Fax To Quit would be beneficial to informed future programming.

Quickly, about the methodology about our survey. CTC in New Jersey has done many, many surveys with OB/GYNs and nurse midwives in the past. This survey we implemented with the OB/Gyns and nurse midwives is a revision of a 2002 instrument. So this instrument is a cross sectional mailed questionnaire. Here are some of the topics within that survey that we think are most relevant to today's talk. The survey took about 15 minutes and we did offer an incentive. We had a 157 eligible completes. This was a representative sample. Our response rates were 67.8 percent for the nurse midwives and 60 percent for the OB/GYNs, which is a pretty good response rate. Here's demographics of our survey participants. This does mirror what the OB/GYNs and nurse midwives in New Jersey look like as a whole. So this was great to demonstrate the representativeness. Quickly these are the five A's, ask, advise, access, assist, and arrange. Like I mentioned earlier, we always have ask and advise. It's getting down when we talk about assisting, and then following with arrange that are the problems in New Jersey. So we're hoping implementing something like Fax To Quit might help increase these types of numbers. The barriers, some of the barriers that are noted by OB/Gyns and nurse midwives, the bars are strongly agrees the darker color, somewhat agree is the lighter color. So lack of patient interest in tobacco interest seem to be the number one item from OB/GYNs. Point of view that was a barrier to providing treatment. The other four are competing priorities, patient resistance, lack of time, and lack training. All five of those barriers were the top five for both the OB/Gyns and nurse midwives. What we're hoping with Fax To Quit is that the lack of time and the lack training, an competing priorities issues will become less of a barrier for these providers

because we'll be saying, "Just ask them if they're smokers, access if they want to quit, and then refer them to quit line, and we'll take it from there.

These are some of the data from the Fax To Quit portion of the survey. It's a little tricky to see this. We know that about 10 percent of OB/GYNs are familiar with some kind of Fax To Quit program. Very great numbers here. We've got a very high number of folks who think that patients would benefit from the program, about 87 percent said they would use a fax-equipped program. They say that the patients would accept a call from the program, which is a fantastic thing. And I'm just going to move on now to the nurse midwives. I want to point out here that 100 percent of the nurse midwives in the survey say that they would use a fax-equipped program. So the data here suggests that the fax-equipped program is something that we think is certainly feasible in New Jersey. Very quick discussion points. A large proportion of respondents agreed that patients would benefit. We know that nearly all the respondents agreed that they would use fax-equipped program. I'm going to skip right down to the bottom. We have determined in New Jersey that doing a feasibility study of Fax To Quit is certainly a warranted thing. So I'll wrap from there.

PATTY DIETZ: Thank you, Heather. Next we'll hear from Kate from Wisconsin.

KATE KOBINSKY: Thanks Patty. Good afternoon. So I'll wrapping with a panel presentation by talking about the Wisconsin experience. And first I just want to highlight two population based tobacco cessation services for Wisconsin's pregnant smokers.

The first is the quit line, and the second is the Wisconsin Women's Health Foundation's First Breath program. So just a couple of points about the quit line. We've had our quit line since 2001, and our Fax To Quit program since 2003. I just want to highlight that in recent years we felt like our Fax To Quit program has been very successful. We have over 400 registered Fax To Quit sites across the state. They're largely primary care providers, but also in the hospitals, pharmacies, dentists, but largely primary care. And the success rate has been about 50 percent enrollment rate among women who are actually referred to the quit line. So of all the submissions that the quit line gets from providers about 50 percent of those women actually accept services. That's a big change from when we first started. The first few years we had about a 15, 20 percent enrollment rate, and I won't talk about it, but over the years we did a number of quality improvement initiatives to improve that. And then you can just see some of the services that are available through our quit lines, some of them pregnancy specific.

So the First Breath program is who partnered with in this project. They're statewide program. They largely target low-income pregnant women, have about 100 participating providers across the state. They're largely at local health departments. So they're providing prenatal care coordination and WIC services. The quit line and the Fax To Quit program have been aggressively promoted at these First Breath sites over the years. Look at Wisconsin today, 15 percent of pregnant smoke, one percent of our quit lines users are pregnant women. Only seven percent of First Breath clients report having contact with a quit line in 2008. And despite the fact that about half of the First Breath sites are registered Fax To Quit program sites too, few are referring their clients

to quit line through Fax To Quit. So that raised some questions for us. We wanted to know what are the barriers at the First Breath sites to actually making referrals through Fax To Quit and what features of the program work at these sites. We also wanted to know right from prenatal smokers what their barriers are to using the quit line. So our methods were first to recruit ten First Breath Fax To Quit providers. We actually did want to recruit non First Breath Fax To Quit providers, but we weren't able to that, so we were limited to First Breath providers only. And we also wanted to get a range of Fax To Quit activity among these providers so that we were really getting a perspective from everyone one. So we were able to recruit two that were considered high referrers, four moderate, and four low. Then we conducted in person in-depth interviews with these providers to ask them about what do you know about the quit line? How do you actually promote it? How do you implement the Fax To Quit program? What are your barriers? Why do you feel that pregnant women aren't using it? And then followed that with a survey of postpartum women. Each of these ten sites invited all eligible women whether they were a First Breath client or not to take part in the survey. We asked them about their smoking behaviors, their quitting methods, their knowledge and attitudes about the quit line. And this survey actually administered at the postpartum visit, which was generally six weeks after delivery.

So jumping right into the provider interviews and you're going to hear some common themes from what Heather and Bob were talking about. We asked them what the barriers to implementing Fax To Quit? Well over and over we heard about, "I just don't have enough time with a patient and the patient really has higher priority needs,

whether it's other alcohol and drug use, their being evicted from their home, they don't have a job. So they feel that in the hierarchy of needs quitting tobacco falls at the bottom." We also found that despite being trained on the quit line and Fax To Quit initially and offered continuous ongoing training. They lack knowledge about what services are available through the quit line and exactly how Fax To Quit works. Many of them weren't aware that the quit line offered an enhanced pregnancy program with additional calls. And I heard this a number of times, "I don't know how to sell it to my clients. I don't know how to promote it." We also found that Fax To Quit wasn't being systematically integrated into some of these sites, so they lacked reminders, so they just forgot to even offer Fax To Quit to clients who were a good candidates. Half of them referred all tobacco users to the Fax To Quit program. In Wisconsin our protocol is that if you are interested in quitting in the next 30 days and you're willing to accept calls from the quit line, you are an ideal candidate for Fax To Quit. If neither of those conditions are true we recommend that they provide other tobacco cessation resource information including providing the 800 number for the quit line. And I think that that point referring all tobacco users leads to this very last point, which is providers are just frustrated that referrals aren't resulting in connection, so they just don't do it.

We asked providers what they perceived to be patient barriers to the quit line. We also heard about telephone issues. Provider said, "Patients just are not interested," and providers perceive that to be they're not ready or they want to quit on their own. We heard that all the time, "They want to quit on their own." We also heard that patients have a fear of the unknown. They don't know what to expect when they call the quit line.

One provider said they were afraid they'd get yelled at. And the one unique thing about the First Breath program is that a client engages with the same provider throughout pregnancy and public health nurse, throughout pregnancy and as long after delivery as possible. So they're really building a relationship with this provider and they're getting their tobacco cessation, they feel they're getting their needs met through this provider, so they don't feel that they need to call this unknown 800 number and talk to someone they perceive to be a stranger. That was a barrier that came up many times. So then we asked providers what makes the Fax To Quit program work at your site? Well the disheartening thing here was that most providers really weren't able to tell us something that made the Fax To Quit program work. The one exception was that we -- and this was the highest referrer of all the sites by three time as many referrals, they actually offered a gift card, a \$10 gift card to all clients for having at least one contact with the quit line through Fax To Quit. So it clearly had an impact on getting clients to connect with the quit line. What we don't know is whether that leads to more quit attempts or more successful quits.

So our conclusions were that despite that one difference of using the \$10 gift card, there were apparent differences between high, moderate, and low referrers. Fax To Quit needs to be systematically integrated into provider sites, so that you're reminded to use. Providers need to be able to give patients a better understanding of how the quit line works and that includes taking us up on the offer of refresher trainings on the quit line and Fax To Quit, utilizing our Fax To Quit manual, and I'll just show this up as a visual aid. We actually have a manual that is \*\*\*\* behind resource and all ten of the sites said

they didn't use it. It has some really great resource in it, referring only those ready to quit, and then actually having providers call the quit line themselves, so that they can speak one-on-one with the quit line, get a real sense of how it works, and be able to communicate that to patients in a way that they're confident in talking about it. We also think it'd be important to insure ways for these patients with phone issues to actually connect with the quit line. That's pretty difficult, but maybe a provider can offer some prepaid phone minutes. Maybe they can provide a phone and access to that phone for clients. And then we just feel that we need more research regarding use of incentives to use the quit line services. What's the actual effect of that?

So moving on to the second part of our project which is the survey of the postpartum women, you can see the demographic information here. We had 149 respondents again, and it was offered to all eligible women. We only had five refusals. We asked women their knowledge and perceptions of the quit line. We have found some good news here, most were aware of the quit line. They believed it to be effective, and yet only nine percent, 14 women actually reported using the quit line for help during pregnancy. We asked them about their quit attempts. Eighty percent of the entire sample made a quit attempt during pregnancy. How did they quit? Well a few used medications. That's not too surprising due to the fact that the clinical practice guidelines doesn't make a recommendation about medication use during pregnancy. And here in this graph you can see this is the disheartening thing that with the exception of the First Breath program cutting down slowly, cold turkey, and I just tried to quit on my own were the top three methods of quitting. So clearly not using evidence based methods. We



asked them about their barriers to using the quit line and the Fax To Quit program. The top two reasons that they listed were, I want to quit on my own, and I didn't think the quit line would help. So seems like they believe the quit line can be effective in helping people quit, it's just not going to help me quit. We asked them an open-ended question, what would motivate you to call the quit line? We saw a few themes immerge here, but generally it just still seems unclear to me being ready to quit, not being able to do it my own, and I don't know was big response. We also asked who suggestion would motivate you to call the quit line. The biggest response here was I don't know. But one positive was that we did see women frequently chose multiple people, and nurse and doctor were the top two there. We asked them about their healthcare provider involvement. Here we saw some good news. Ninety seven percent were asked about their smoking, 63 percent say that their healthcare provider talked about the quit line. That was good. We weren't expecting a rate that high. Twenty three percent of the women were offered Fax To Quit and of those, 32 percent accepted that referral. Now when we drilled a little further down and looked just at the 14 women who used the quit line we see some improvement in those numbers. Ninety three percent were asked about their smoking. All of them say their healthcare provider talked about the quit line. Seventy nine percent were offered Fax To Quit, and of those 71 percent accepted. So some big jumps there in the Fax to Quit portion.

So our conclusions with the postpartum survey are that most were aware of the quit line, believed it to be effective, few used it. It's unclear what would motivate pregnant women to use the quit line, but Fax referral does show promise to improve utilization. It

seems that the healthcare provider referral could have made the difference for those ten women, who say that their healthcare provider intervened to get them to the quit line. We don't know what the role of the \$10 gift card was from that one highest referring site, and clearly we need to understand more about what is it about I want to quit on my own. What does that mean first of all? I wish I could go back and do some probing questions. I don't understand what that means, I want to quit on my own. And just this general reluctance to use evidence based treatments.

So in conclusion pregnant women who smoke aren't regularly connected to evidence based quitting service, and First Breath providers, which the population we were talking to, and their pregnant smokers just generally seem ambivalent about quit lines. Now I would say that pertains more so to the pregnant smokers. That doesn't mean like I talked to the First Breath providers, it doesn't mean they don't think it's a good resource and they sure would like to see their clients use it, but it's just not happening. And the last thing that I really want to emphasize here is, again we're talking are really unique group of providers, these First Breath providers that are establishing a face-to-face relationship with their clients, and their seeing the same provider throughout pregnancy and as long after delivery as possible. Now with our general Fax To Quit program it's primarily in primary care where you may see somebody different and you don't see them as often. Fax To Quit has been very successful there, and I just wish we could have recruited non-First Breath providers, some OB/GYNs to get a little more perspective on that. So I don't think that Fax To Quit can't be used with -- or wouldn't be

successful with the prenatal population. We just had a really unique group of providers we are working with here. So that wraps up my presentation, and I'll turn it over to Patty.

PATTY DIETZ: Thanks. I want to open up to those of you in the audience. You have any questions or if you want to talk about what programs you're currently involved in your community.

UNKNOWN SPEAKER: My name is \*\*\*\* Ashley. I work for the \*\*\*\* Health Bureau and we really appreciated your presentations. Before it came to Maternal Child Health Bureau we also \*\*\*\* health to working very closely at \*\*\*\* opposite women's health regarding these issues. And I had a couple questions there are things that like \*\*\*\* discuss further. I know that sometimes when you present you say that, well in all fairness they didn't do this \*\*\*\*. I'm really familiar with the findings, and I wanted to in the case of the OB's is that really spends a lot of time looking into this, looking at the \*\*\*\* and some look more into, you know, that they use for documentation. I think we're looking at it the right way. We recently \*\*\*\* that way is most of know about your positions \*\*\*\* that are not \*\*\*\*. You know OBs very much work in teams. And I know when I watched \*\*\*\* colleagues for OBs many time they do more than the first \*\*\*\*. Maybe he tried to do more than they asked. They usually ask also, "Are you ready to quit?"